

Paper: Exploring Internet and Media-mediated Health Information within the Context of Personal Health Management

Abstract: This qualitative paper explores how health information mediated by the internet and media is used and made valuable within the life of consumers managing non-crisis health challenges, and how informal information seeking and gathering influences self-positioning within patient-clinician relationships. Findings have implications for health information literacy and collaborative, patient-centred care.

Résumé:

Cette étude qualitative explore comment l'information sur la santé relayée par Internet et les médias est utilisée et rendue utile dans le contexte de consommateurs gérant des problèmes médicaux non urgents, et comment la recherche et la collecte d'information informelles influencent l'auto-positionnement dans la relation patient clinicien. Les résultats ont des applications dans la maîtrise de l'information médicale et les soins collaboratifs centrés sur le patient.

1. Introduction

At the same time as information and health professionals are seeking to encourage the use of 'evidence-based' information sources, thus discursively constructing 'appropriate' and 'inappropriate' medical information (see for example, Hanif et al. 2009; Perez-lopex 2004), consumers are drawing from and relying on health information mediated by a wide range of formal and informal sources (Fisher & Julien 2009; Genuis In press; Harris & Wathen 2007;). An escalating number of people are, for example, relying on the internet for important health information (Madden & Fox 2006), and a Cochrane systematic review notes that both in cases of planned media publicity campaigns and in cases of unplanned media coverage "mass media are the leading source of information about important health issues" (Grilli, Ramsay, & Minozzi 2002, 2). Focusing on information behaviour (IB) within the context of non-crisis personal health management, this paper moves beyond identification of specific information sources (see for example, Warner & Procaccino 2004) and seeks nuanced understanding of how health information mediated outside of the patient-clinician encounter is used and made valuable within people's everyday lives. The influence of informally mediated health information on collaborative self-positioning and decision-making within the context of the patient-clinician relationship is also examined.

This paper draws on a study which examined the ways in which women navigating the menopause transition responded to, made sense of, and used (or did not use) health information mediated by formal and informal information sources (Genuis In press). Based on Archer's (2007) assertion that the rapid decline of hormone therapy (HT) prescribing and use following publication of results from the Women's Health Initiative study (Rossouw et al., 2002) "dramatizes the influence of the media and the Internet on

the practice of medicine in the 21st century” (Archer 2007, 29), this exploration focuses on internet and media-mediated health information, illuminates health professionals’ (HPs) perceptions of patient interaction with these informal information sources, and discusses implications for information professionals and HPs. Exploration of online and media-related IBs are anchored within the everyday and offline contexts of health and health IB (Kivits 2009).

2. Theoretical framework

This paper is based on a social constructionist approach and an active, process-oriented view of IB (Dervin 1992). It explores “general sense-making practices on the basis of which people orientate themselves in their everyday and working lives” (Talja, Keso, & Pietilainen, 1999, 761) and considers outcomes which include use and non-use of information and end-products which may consist of knowledge, opinion, intuition, evaluation, and affective response (Dervin 1992). Social positioning theory (Davies & Harré 1990; van Langenhove & Harré 1999) provides a lens for exploring the dynamic aspects of information encounters.

3. Research methods

Data was gathered from semi-structured qualitative interviews with a sample of women engaged in IBs related to the menopause transition (n=28) and with a smaller sample (n=12) of HPs (physicians, pharmacists, nurses, dieticians, and alternative health practitioners) acting as information providers for this population of women. Samples were recruited in the community and at a multidisciplinary, publically funded menopause clinic. Two interview strategies were used during interviews with women. A semi-structured, narrative approach allowed participants to relate and construct their information-seeking and health-related experiences “in their own terms” (Petersen, 2006, 34). Second, ‘in-the-moment’ elicitation (Johnson & Weller 2002) was used: three articles with contrasting information relevant to this population (CBC, 2007a, 2007b, 2008) were sequentially presented to women with discussion focusing on women’s reactions to media-mediated health information and integration of that information with health information from other sources. Semi-structured interviews with HPs focused on themes emerging from interviews with women, thus supporting analytic rigor by confirming and augmenting themes (Creswell 1998). HPs’ perceptions of women’s IB and of their own roles as information providers were also explored. Data analysis, facilitated by NVivo 8, incorporated directed content analysis guided by theory (Hsieh & Shannon 2005) and grounded theory’s constant-comparative method (Glaser & Strauss 1967).

4. Results

Although its importance as an information source varied, use of the internet for seeking health information was ubiquitous and explicitly valued in this sample of women. Online information searching was presented as part of a continuum of information gathering and was seamlessly integrated with other approaches to information seeking. Online information provided initial introductory information when women encountered health concerns, facilitated deeper exploration of health topics, confirmed information provided by other sources, provided alternative strategies for health management, and allowed participants to explore health information at their own pace and to the level of detail which they desired. The internet emerged as a hybrid source not only because it

provided access to both formal (for example, the Mayo Clinic website) and informal (for example, interactive discussion lists) sources, but also because it provided access to both static didactic information and interactive platforms. For many participants, the internet served as a diagnostic tool and as a critical resource for normalizing their experiences and addressing uncertainties about menopause as a life stage. Participants were aware that the credibility of online sources varied and the majority of women identified some assessment criteria which they applied to internet websites and information. In all cases, women viewed the internet as a resource which empowered them within the patient-clinician relationship and as decision-makers. While health information seeking via the internet was intentional for this sample of participants, health information in the media was generally encountered incidentally. The media was, however, explicitly valued as an awareness tool which empowered women with knowledge that was not necessarily provided by HPs and which served as a springboard for subsequent information seeking. HPs in this sample tended to be leery of the influence of the internet and media on women's decision-making and expressed concern about the 'noise' created by the mix of research-based and informal health information encountered via these mediums.

5. Implications and significance

With online information seeking transforming traditional models of health communication (Fox 2005) and claims that the mass media dramatically influenced decision-making for women experiencing this life transition (Archer 2007), deeper understanding of how people interact with and integrate informal sources of health information is critical to facilitating health information literacy and collaborative patient-HP relationships. Health information literacy has traditionally focused on formal, 'evidence-based' resources and decision-making has been positioned as a HP-mediated process: "transferring technical information, making sure patients understand this information, [and] helping patients base their preference on the best evidence" (Légaré & Brouillette, 2009, p. 170). Findings from this study, however, demonstrate that varying mediums fulfill women's information needs in different and complementary ways. In order to facilitate user-centred health information literacy and collaborative decision-making, it is critical that information professionals and HPs consider how consumers use and value informal sources, such as the internet and media, and how these mediums influence self-positioning and health decision-making.

This study has important practical implications for professionals in both Library and Information Science and in the Health Sciences. In order to meet the information needs of people engaged in personal health management, support and guidance should be provided for navigating informal information sources. Women were aware of the varying authority and quality of websites; findings suggest that consumers will be empowered by basic understanding of research terminology and methods, as well as by generic assessment skills. This will allow constructive interaction with information about health research which is covered in the popular press and discussed online. Furthermore, data demonstrated that women were more likely to position themselves as collaborators and express trust in formal information when HPs demonstrated (1) interest in information exchange as opposed to limiting themselves to information delivery, (2) an appreciation for different types of knowledge and cognitive authority, and (3) support for women as they sought and gathered health information from a wide range formal and informal sources.

6. Relationship to conference theme

By providing nuanced insight into women's complex information worlds, particularly the influence of internet and media-mediated health information, this paper directly contributes to understanding of how health information is used, made sense of, and understood. The paper is specifically relevant to the following conference themes: *Information in a global world*, and *The Internet as a source of local and global information*.

References

- Archer, David F. 2007. Medical decisions regarding hormone therapy for menopausal women are significantly influenced by the media. *Pharmacoepidemiology & Drug Safety* 16 (1): 28-31.
- CBC. 2007a. Take vitamin D to reduce cancer risk, Canadian Cancer Society advises. Canadian Broadcasting Corporation. <http://www.cbc.ca/health/story/2007/06/07/vitamin-d-recommendations.html>
- . 2007b. Vitamin D lowers cancer risk in older women: Study. Canadian Broadcasting Corporation. <http://www.cbc.ca/health/story/2007/06/07/vitamin-d-cancer.html>
- . 2008. Calcium, vitamin D not linked to reduced breast cancer risk: Study. Canadian Broadcasting Corporation. <http://www.cbc.ca/health/story/2008/11/11/calcium.html>
- Creswell, John W. 1998. *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks: Sage Publications.
- Davies, B., and R. Harré. 1990. Positioning: The discursive production of selves. *Journal for the Theory of Social Behaviour* 20 (1): 43-63.
- Dervin, Brenda. 1992. From the mind's eye of the user: The sense-making qualitative-quantitative methodology. In *Qualitative research in information management*, eds. J. Glazier, and R. Powell, 61-84. Englewood, CO: Libraries Unlimited.
- Fisher, Karen E., and Heidi Julien. 2009. Information behavior. In *Annual review of information science and technology*, ed. Blaise Cronin, 317-358. Vol. 43. Medford, New Jersey: Information Today, Inc.
- Fox, Susannah. 2005. Health information online. Pew Internet & American Life Project. http://www.pewinternet.org/~media/Files/Reports/2005/PIP_Healthtopics_May05.pdf
- Genuis, Shelagh K. In press. Constructing 'sense' from evolving health information: A qualitative investigation of information seeking and sense making across sources. *Journal of the American Society for Information Science and Technology*.
- Glaser, B., & Strauss, A. 1967. *The discovery of grounded theory*. New York: de Gruyter.

- Grilli, R., C. Ramsay, and S. Minozzi. 2002. Mass media interventions: Effects on health services utilisation. *Cochrane Database of Systematic Reviews 2002*, Issue 1. Art. No.: CD000389.
- Hanif, Faisal, Janet C. Read, John A. Goodacre, Afzal Chaudhry, and Paul Gibbs. 2009. The role of quality tools in assessing reliability of the Internet for health information. *Informatics for Health and Social Care* 34 (4): 231-43.
- Harris, R., and C. N. Wathen. 2007. Searching for health information in rural Canada. Where do residents look for health information and what do they do when they find it. *Information Research* 12 (1): paper 274. <http://InformationR.net/ir/12-1/paper274.html>
- Hsieh, H.F., and S.E. Shannon. 2005. Three approaches to qualitative content analysis. *Qualitative Health Research* 15: 1277-88.
- Johnson, Jeffrey C., and Susan C. Weller. 2002. Elicitation techniques for interviewing. In *Handbook of Interview Research: Context and Method*, eds. J. F. Gubrium, and J. A. Holstein, 491-514. Thousand Oaks: Sage Publications.
- Kivits, Joelle. 2009. Everyday health and the internet: A mediated health perspective on health information seeking. *Sociology of Health & Illness* 31 (5): 673-87.
- Légaré, France, and Marie-Hélène Brouillette. 2009. Shared decision-making in the context of menopausal health: Where do we stand? *Maturitas* 63 (3): 169-75.
- Madden, Mary and Fox, Susannah. 2006. Finding answers online in sickness and in health. Pew Internet & American Life Project. <http://www.pewinternet.org/Reports/2006/Finding-Answers-Online-in-Sickness-and-in-Health/Report.aspx>
- Perez-Lopez, Faustino R. 2004. An evaluation of the contents and quality of menopause information on the World Wide Web. *Maturitas* 49 (4): 276-82.
- Petersen, Alan. 2006. The best experts: The narratives of those who have a genetic condition. *Social Science & Medicine* 63 (1): 32-42.
- Rossouw, J. E., G. L. Anderson, R. L. Prentice, A. Z. LaCroix, C. Kooperberg, M. L. Stefanick, R. D. Jackson, et al. 2002. Risks and benefits of estrogen plus progestin in healthy postmenopausal women: Principal results from the Women's Health Initiative randomized controlled trial. *Journal of the American Medical Association* 288 (3): 321-33.
- Talja, S., H. Keso, and T. Pietiläinen. 1999. The production of 'context' in information seeking research: A metatheoretical view. *Information Processing and Management* 35: 751-63.
- van Langenhove, L., and R. Harré. 1999. Introducing positioning theory. In *Positioning Theory*, ed. R. Harré and L. van Langenhove, 14-31. Oxford: Blackwell Publishers Ltd.
- Warner, Dorothy, and J. Drew Procaccino. 2004. Toward wellness: Women seeking health information. *Journal of the American Society for Information Science &*

